Health related quality of life in people with multiple sclerosis

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Chapter 8

General discussion, implications and conclusions

This thesis focuses on psychological and social variables in people with multiple sclerosis (MS) in regard with their health-related quality of life (HRQoL). The individual topics were formulated as specific research questions and addressed in chapters 3-7. The general discussion firstly provides a brief overview of the main findings (8.1) and the next part brings about discussion of these findings (8.2). The following part addresses strengths and limitations of this thesis (8.3). Implications of the study along with possibilities for future research are summarized in the last part (8.4).

8.1 Main findings

Research question 1 (Chapter 3)
Are different coping strategies associated with different levels of health related quality of life?
We found that all three studied types of coping (problem-focused coping, emotion-focused coping and coping focused on stopping unpleasant emotions and thoughts) were positively associated with the Mental Component Summary (MCS) of Health-Related Quality of Life (HRQoL), but were not associated with the Physical Component Summary (PCS) of HRQoL. In PCS significant associations were found with physical disability, as measured by the Expanded Disability Status Scale (EDSS) and disease duration. While all three coping strategies showed significant associations with MCS, coping focused on stopping unpleasant emotions and thoughts explained most of the variance in our model of linear regression analyses, suggesting the relative strength of this type of coping.

Research question 2 (Chapter 4)
Is social participation associated with the physical and mental components of quality of life?
We found that there is a positive association between social participation and PCS along with functional disability measured by the Expanded Disability Status Scale (EDSS) and disease duration. These variables were also significant in explaining most of the variance in the PCS model. A

significant association between social participation and MCS was found as well, but the statistical model as a whole was not significant. Neither sociodemographic variables, nor clinical variables seemed to be associated with MCS either.

Research question 3 (Chapter 5)
Do different coping strategies mediate the association between fatigue and health-related quality of life?
In PCS, different coping strategies showed different results. Problem-focused coping and emotion-focused coping significantly mediated the association between general fatigue (GF) and HRQoL. Coping focused on stopping unpleasant emotions and thoughts showed a significant indirect effect in case of GF, physical fatigue (PF) and reduced motivation (RM). Reduced activity (RA) and mental fatigue (MF) were not mediated by any of the studied coping strategies. In MCS the mediations were presented for each fatigue form and every coping strategy. The highest indirect effects overall were found in coping focused on stopping unpleasant emotions and thoughts.

Research question 4 (Chapter 6)
Do different coping strategies mediate the association between Type D personality and health related quality of life?
It was found that in PCS coping did not mediate the association between Type D personality and HRQoL. The direct effect of Type D personality on PCS was strong and coping was not associated with their interaction. In MCS, however, all three coping strategies mediated the association between Type D and HRQoL. The highest indirect effect (45%) was found in coping focused on stopping unpleasant emotions and thoughts.

Research question 5 (Chapter 7)
What is the effect of self-esteem on the association between social participation and health related quality of life?
Self-esteem did not mediate the association between social participation and PCS; only the direct association between these two variables is significant. Self-esteem on the other hand mediated the association between social participation and MCS.

8.2 Discussion of the main findings

This thesis focused on factors associated with health related quality of life (HRQoL) in patients with MS. Our main points of interest were variables of coping, social participation and self-esteem and their associations with PCS and MCS. Our study is also partially inspired by the ICF model where social participation plays important role associated with disability.

This model also stresses the existence of interactive associations between various factors which is beneficial in getting a more comprehensive view on HRQoL in patients with MS. Based on our research questions we derived our own theoretical model where research questions are centered around HRQoL as a variable we find crucial for patients with multiple sclerosis (MS) (Figure 8.1). Results from this thesis are summarized below (Table 8.1).

Figure 8.1 Design of the variables used in the study

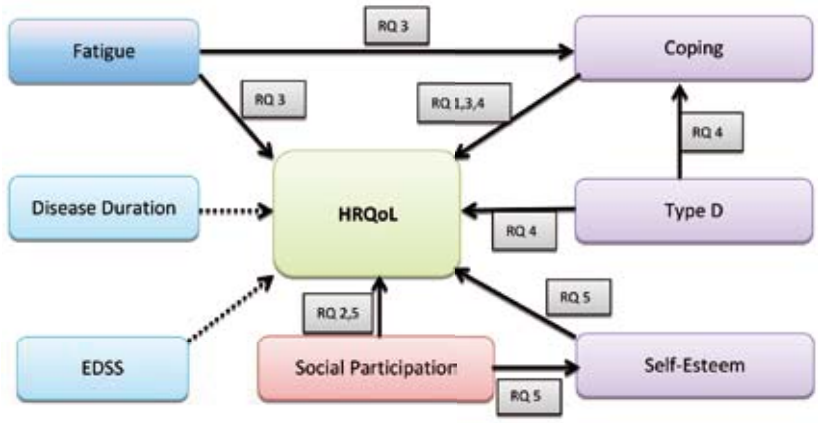

Table 8.1 Main results of the thesis

	HRQoL	
	PCS	**MCS**
Coping		
Problem-focused	-	+
Emotion focused	-	+
Stopping	-	+
Social participation	+	-
Fatigue		
General fatigue	+	+
Physical fatigue	-	+
Reduced activity	-	+
Reduced motivation	+	+
Mental fatigue	-	+
Type D	-	+
Self-esteem	-	+

8.2.1 Coping self-efficacy and quality of life in patients with multiple sclerosis

We found that the mental component of health related quality of life (MCS) is associated with all coping strategies and that coping self-efficacy is a part of the complex associations between Type D personality and fatigue. All three coping strategies seem to be important for MCS, not only in patients with multiple sclerosis (MS) but also with various other chronic conditions [1-4].

In our study, coping seems to have a mediating effect on a number of variables. Fatigue as one of the most common symptoms of MS seems to be mediated not only in MS but also in other chronic conditions [5,6]. The most explanatory of the three studied coping strategies seems to be coping focused on stopping unpleasant emotions and thoughts. In patients with MS, this coping strategy explained the most variance of all the coping strategies in MCS and mediated the associations of both fatigue and type D personality with MCS with the highest effect. No optimal cure for MS has been found so far [7,8] leaving patients without the ability to control the disease directly. With having very little control over their disease and its course due to its chronic nature and unpredictable set of symptoms [9,10], active coping strategies may not be the most efficient for people with MS. Stopping unpleasant emotions and thoughts can thus effectively reduce the stress that MS brings and improve patient's MCS. This interpretation is in line with previous studies which suggest that this coping strategy is more adaptive when little control is possible, which is true for the situation of MS patients [11,12].

On the other hand, our results showed that regarding PCS, the role of coping was not significant or at least not significant as on the level of MCS. For the most part functional disability measured by the expanded disability status scale (EDSS) was the main predictor of PCS. This result is in line with existing studies dealing with coping and quality of life [13,14], although in some other diseases, this association seems to be significant [15,16]. The reason why PCS was not prominently associated with any type of coping might be due to the fact that residual persisting neurological symptoms cannot be suppressed by coping strategies. Adverse inflammatory processes take place in the brain tissue even if patients use coping strategies effectively [17]. Thus, PCS might be only marginally modified by a psychological resource such as coping.

Some studies focused also on quality of life of caregivers who live in the same household with the MS patient, but they did not come up with similar results. Especially coping focused on getting support showed a negative association with quality of life in caregivers [18]. Caregivers, although forced to adapt to symptoms of MS in their household, may not experience same feelings as people they are taking care of [19].

8.2.2 Social participation, self-esteem and quality of life in patients with multiple sclerosis

Findings from our study indicate that social participation is associated with PCS but not with MCS. Although the beta coefficient of social participation suggests some weak association with MCS, the overall model is not significant and in chapter 7 social participation shows a significant association with PCS only. Furthermore we found that self-esteem on the other hand does not seem to be associated with PCS, but is associated with MCS. This finding is in line with an earlier study [20]. The rationale for these findings may be in the physical nature of MS [21,22]. Participation in social life is based on the ability to go, move, transport and physically meet with other people. Movement may be very limited in later stages of MS [23-25] and thus preventing the positive effect of social participation in building and maintaining friendships, being part of community whether it is work, religious or hobby oriented or engaging in culture experiences. Self-esteem, although also important in social life [26], is a very subjective and internal variable and thus may not be dependent on physical ability [27]. In our findings self-esteem is associated with MCS and it also mediates the association between social participation and MCS, indicating that self-esteem can have a positive impact on these variables.

8.3 Strengths and limitations of the study

One of the strengths of this study is the high response rate within our sample (72.9%). The approach regarding social participation on the basis of peer comparisons in relation to HRQoL is also a strength of this study, as it gives us a better understanding of social participation in the specific condition of a chronic disease and not only a comparison with the general average population. The consecutive method of collecting data and the complex modelling of variable interactions also belong among the strong points of this study.

Some limitations should be noted, however. Although the women-to-men ratio in MS is 2:1, in our sample the ratio was higher (75.0% women), so the results may better explain the quality of life of women more so than men. Also, patients with a lower disease severity (mean EDSS 3.2) were more likely to participate in the study, while patients with a more serious disability were more likely to refuse to participate. Regarding personality, we used Type D, and in the case of coping we used coping self-efficacy, so our findings should be generalised with caution to personality or coping measured in different ways. In addition, due to the cross-sectional design any causal relationships drawn from our results should be interpreted with caution.

8.4 Implications

8.4.1 Implications for clinical practice

This thesis is beneficial in bringing a new view on avoidance coping. Stopping unpleasant emotions and thoughts showed in our results to be an adaptive and helpful characteristic for patients with MS. Although this type of coping may seem to be maladaptive, in our sample it helped to improve the mental component of quality of life. It also showed significant effects in the mediating associations between coping, fatigue and MCS and between coping, Type D and MCS with the highest levels of statistical significance from the three studied coping strategies. The clinical importance of this study is that MS patients should consider using this type of coping in dealing with their condition. Physicians, caregivers, psychologists, psychotherapists and patients themselves should be educated about various ways of coping with their disease and encouraged to live a life without constant worries about their symptoms or the progress of their disease and thus improve their MCS. Another part of education of patients, caregivers and all professionals taking interest in patient with MS can focus on reducing the effect of coping on the association between fatigue and PCS but especially MCS, where coping may act as a protective factor. Similar recommendations can be stated for type D personality and although we believe that type D personality traits are fairly stable, coping strategies can actively be modified and possibly bear an effect on depressive and anxiety related symptoms associated with negative affectivity and social inhibition of type D personality and thus be of great use in diminishing the adverse effects of type D on MCS. MS clubs could apply these outcomes during discussions/educational programs with MS patients, where psychologists or trained caregivers could talk with patients about the various ways of coping with their disease. Physicians could also benefit from the knowledge about different ways of coping with stress, especially in the early stages of the disease when patients are still learning how to live with a new diagnosis of MS. Even patients with longer disease duration could make use of these findings if their coping strategies have so far proved to be ineffective. These findings can also be implemented into the psychological therapy process. Cognitive Behavioural Therapy (CBT) may work with stopping unpleasant emotions and thoughts in patients with MS [28]. Various forms of treatment working with techniques that can diminish the effect of fatigue in patients with chronic conditions [29,30], either in long individual therapies or education about the role of coping, can be included in shorter pragmatic programs too [31].

This study is also beneficial in that it shows that social participation is very important for PCS in MS patients. According to our results, isolation and avoiding social activities are associated with lower HRQoL in patients with MS. Hiding from social activities may seem comfortable and easy as it

eliminates the stress from obstacles in social participation caused by health problems, but this study indicates that people who don't engage in social participation have a worse PCS. Additionally various ways of improving self-esteem can be applied for the benefit of MCS. It can be modified, for example, by social support aforementioned social participation and physical activity [32]. Social support has been found to have a protective effect from various adverse effects on MCS [33], so encouraging and education of caregivers and relatives about positive social support for self-esteem is important. Physical activity is another protective factor of self-esteem, not only in terms of affecting the weight of patients, but also for neurochemical processes and leisure-time management [34,35]. These activities have a high potential to bring results, as self-esteem seems to be very responsive to educational programs and can be improved [36]. Thus, patients with MS should be educated about ways in which social activities can benefit them and should be encouraged to engage in social participation even if physical obstacles make it more difficult. These recommendations along with the ones from research focused on coping, can be used together in a series of educations seminars supplemented by role play model situations, social games and introspective sessions in order to create a full fleshed unit on how to improve some of the aspects of HRQoL. This can also be beneficial for caretakers and physicians of MS patients who can benefit from education about coping with non-treatable disease as well. They can be included in social games focused on social participation as well and with better understanding of MS, they can be more effective and understanding of various challenges it brings. Psychologists working with people with MS may use these results as a basis for therapy sessions, use them in rehabilitation of patients, training of daily activities or help them with changing coping strategies with longer disease duration and disease progression.

8.4.2 Implications for future research

Coping seems important in various associations of HRQoL with other variables in multiple sclerosis. Future research is needed though, to see if it shows similar results in other chronic conditions, along with control studies of healthy population and caregivers. Also longitudinal studies on how coping strategies change with longer disease duration, how social participation evolves with more symptoms and how fatigue, type D and self-esteem change their associations with more impairments caused by MS should be done in order to determine causality of studied associations. Similar research in other chronic conditions like Parkinson's disease rheumatoid arthritis, fibromyalgia and others are also needed in order to generalize these results on populations with chronic diseases. Randomised Clinical Trial interventions along with a pilot study and subsequent studies of effect of educational program proposed in this

thesis is another point of interest for future research.

8.5 Conclusion

It was found that problem-focused coping, emotion-focused coping and coping focused on stopping unpleasant emotions and thoughts were all predictors of mental component of health related quality of life (MCS) and that all three coping strategies mediated the associations between fatigue and MCS and also between type D and MCS. We also found that self-esteem is a predictor of MCS and mediated the association between social participation and MCS. Social participation by itself on the other hand was associated only with physical component of quality of life (PCS). Coping, social participation and self-esteem may thus play an important role in HRQoL outcomes in patients with multiple sclerosis.

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